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STANDARD-SETTING ACTIVITIES: EVOLUTION OF STANDARDS CONCERNING THE RIGHTS OF INDIGENOUS PEOPLES

Human genome diversity research and indigenous peoples

Note by the Secretariat

Introduction

1. Modern science has developed to the point that scientists are now seeking to trace history and cure disease by investigating human, animal and plant genes. While this practice has been occurring for some time using plant and animal genes, it is only recently that human genes have been used in research. Therefore, the discussion of the ethical and legal issues arising from the use of human genes for research is also relatively new. A parallel development in scientific research generally is the steady move from State-sponsored to privately funded research, and the inevitable influence of the profit motive in this field. As a consequence, many major projects in scientific research, including in the field of human genome research, are conducted by large pharmaceutical companies, not universities or government research institutes.

2. These rapid changes have left some observers feeling that the ethical and legal implications of human genome research have not been taken seriously by those who undertake and benefit from such work. Such implications exist at every stage of the work, including the actual creation of research projects to study human genome material, the collection of samples, the subsequent research and possible manipulation of genes, and the products and results stemming from the research undertaken.

3. Indigenous peoples have come into contact with human genome research predominantly as subjects of research in the Human Genome Diversity Project outlined below. The discussion of the ethics and legality of such research in the context of indigenous peoples should focus on issues of consent to becoming subjects in the HGDP, and of their possible rights to enjoy the benefits of the research, financial, medical and anthropological. The present note does not attempt to judge the Human Genome Diversity Project, but rather provides a starting point for the discussion of the complex and emotionally charged issues surrounding the involvement of indigenous peoples in the HGDP. In the light of resolution 1997/15 of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, which recognizes the need for systematic analysis of this issue, and given the growing debate and apparent mistrust that prevails, it has been thought useful to provide some preliminary information relating to the research in this area.

The collection of human genome samples

4. A genome is all the DNA in an organism, including its genes. Genes carry information for the making of all the proteins required by the organism. The proteins determine how the organism looks, its resistance to disease, and many other characteristics. DNA is made up of four similar chemicals, called bases, and given the codes A, T, C and G for identification. The bases are repeated millions or billions of times throughout a genome. The variety of the combinations of these four bases are the foundation of life's diversity.

5. Before genes were able to be isolated in human tissue or blood, studies were conducted on proteins. There was, however, limited scope for their use in research, as proteins do not vary extensively from one person to the other. During the 1980s the science of molecular genetics matured into the study of stretches of human DNA that do not encode proteins. This led to the discovery of many polymorphisms - DNA sequences that vary from one person to the next. There are thousands of polymorphisms and this diversity allows the identification of previously undetected genetic variation within and between populations.

The Human Genome Diversity Project

6. A major project in human genome research is the creation of an international human gene pool by the Human Genome Diversity Project (HGDP). The HGDP Project aims to collect DNA samples from over 500 linguistically distinct groups across the globe (Nature, vol. 381, 2 May 1996). These groups are to be selected from a possible 7,000 populations worldwide (with Europe being considered separately), determined by a group of anthropologists to be "worthy of study" (Science, vol. 258, 20 November 1992, pp. 1300-1301). The practical working of the Project requires blood or tissue samples from at least 25 individuals from each population, who have given prior "informed consent" at an individual and/or community level.

7. The groups considered "worthy of study" are determined by a number of factors. Isolated population groups are highly valued as they can provide genetic information unique to that group and not "blurred" by mixing with other groups. Many indigenous peoples live in very isolated communities, have therefore kept their bloodlines "pure", and so are highly valued as subjects of the HGDP (Nature, op. cit.). In addition, it is perceived that a number of

these population groups will not exist for much longer because of the trend towards mixing with other population groups or by total extinction. The Project organizers have emphasized the need for haste in order to record the DNA of these groups before they cease to exist: "(e)veryone agreed the highest priority should go to unique, historically vital populations that are in danger of dying out or being assimilated" (Science, op. cit.).

The predicted benefits of the Human Genome Diversity Project

8. Supporters of the HGDP have argued that the Project will have benefits for humanity and for knowledge generally, and more specifically for the participant groups. It is reasonable to state that most supporters prioritize the former. It has been suggested that the HGDP will benefit four major areas of research and hence contribute to the wealth of knowledge of all humankind: the study of human origins and prehistory; the study of social structure, for example mating and marriage patterns; the study of adaptation and disease, for example anatomy, physiology and disease susceptibility; and forensic anthropology (group identification techniques). The creator of the HGDP is Mr. Luigi Luca Cavalli-Sforza, a population geneticist and professor emeritus at Stanford University in California. He argues that the HGDP would enable the creation of a wealth of knowledge of the history of modern ethnic differentiation and human variation. He also emphasizes the identification of links between language and other cultural characteristics and the distribution of genetic profiles throughout the world.

9. More specifically addressing the plight of indigenous peoples and how the Project can help them, Mr. Cavalli-Sforza stated in a paper prepared in 1993 for the United States Senate Committee on Government Affairs regarding the Project that

> "The Project's investigations may make the burdens borne by particular populations public knowledge. The Project can also generate greater public knowledge and interest in cultural diversity and the desirability of maintaining it. It would of course be impossible to reach all populations in need in the course of the Project; there are about 5,000 different populations in the world, based on the count of different languages in existence, and the Project can reach about 10 per cent of them."

In addition, the Project's North American Committee explained in 1994:

> "In the long run, populations that participate in the Project will learn more about their history and origins. Of course, some populations, in both the developed and the developing worlds, may not be very interested in what science deduces about these matters, being content with their own explanations. Nevertheless, even populations that do not seek scientific explanations for their origins may reap long-term benefits from the discovery of useful medical information about their susceptibility to, or treatments for, disease. Because genetic data can also be recovered from bones, teeth, and soft tissues, some populations may also wish to use this approach to help them identify recent or ancient remains that are found in or near their lands."

Concerns raised regarding the Human Genome Diversity Project

10. There has been strongly worded opposition by indigenous representatives and others to the collection of human genome samples from indigenous peoples. The American Indian Law Alliance and other opponents call the HGDP the "Vampire Project", referring to the taking of blood and skin samples from living humans. While all participants in the Project may have concerns, for example ensuring fully informed consent and regarding property rights of information gathered. However, these and other issues surrounding this project appear to affect indigenous groups in a unique manner, for reasons which may include traditional belief structures or a perceived lack of bargaining power. Difficulties with the Project specific to indigenous peoples include the attitude of the Project to indigenous peoples, the perceived violation of their cultural and religious values by interference with the human body, the possible effects the information gained may have for a sampled community, the problems of gaining fully informed consent for the collection of samples from the appropriate power in the community (which may not be just the individual participant), and the participant's property rights over samples and the products of research.

11. The human genome samples are taken from individuals by way of blood donation or the removal of other tissue such as hair or the scraping of skin from inside the cheek. This removal of blood and human tissue is highly offensive to some indigenous cultures in a way not understood by Western science. In addition, the Western scientific practice of trying to divide nature into its smallest elements is the antithesis of indigenous respect for nature as a sacred whole. This is expressed in the Declaration of Indigenous People of the Western Hemisphere Regarding the Human Genome Diversity Project adopted in Phoenix, Arizona, in 1995, which opposes the Project and criticizes efforts of Western science "to negate the complexity of any life form by isolating and reducing it to its minute parts ... and [thereby] alter its relationship to the natural order".

12. Some indigenous peoples see the Project as a new form of colonialism, with sinister overtones; the Western world has taken their land and animals and destroyed their culture, and now it wants to take what is scientifically valuable of the people themselves, and leave them to die out. Indigenous groups have also taken great offence at comments made in the context of the HGDP that their DNA data must be collected before they "disappear", either by extinction or by mixing with other population groups.

13. It is also claimed that the Project is potentially racist as it is based on outmoded notions of race and that human groups may be defined by genetic characteristics but that these vary from group to group in a distinctive manner. At the very least, it is feared that the information will be hijacked for political purposes to support arguments that certain population groups are genetically superior or inferior. A report entitled "Bioethics and human population genetic research" submitted to the third session of the UNESCO International Bioethics Committee in November 1996 pointed out that there is greater diversity within populations than between them and that population geneticists note that population genetics offers no scientific basis for the belief that certain races (however defined) are superior to other races. But,

the report notes, it is of concern that some scientists involved in the Project do not acknowledge that possible racist implications should be a consideration in their work.

14. The Project organizers emphasize that informed consent will be obtained from participants in the Project. Exactly what "informed consent" is and how it is best secured are difficult issues when dealing with isolated communities who have no or little Western scientific knowledge. Informed consent implies that the Project participants are fully informed, and fully understand why the samples are being taken, their rights to samples and the knowledge gained from the study, and the opportunities for financial compensation for the taking of samples and results stemming from them.

15. To explain the extraction of DNA from blood and human tissue and the lessons that can be learned from the results of this work are difficult concepts even for the well educated; to explain them fully to isolated rural peoples may be expected to be even more difficult. Considerable reliance is placed on anthropologists who have had connections with the target population to cross this divide. However, some indigenous representatives are concerned that anthropologists themselves are becoming too involved with "gene hunting" and not enough with the cultural and social aspects of the people they study.

16. Another major difficulty for scientists is to obtain consent for sampling from the correct authority. Understandably, for the scientists, permission is most easily sought from an individual, possibly with the incentive of a medical check-up, or perhaps even with some monetary compensation. Many indigenous communities have a communal or hierarchical decision-making structure that overshadows an individual's right to give consent, particularly when the consent has implications for the entire community. In addition, it is arguably not satisfactory for consent to be given by a community leader without the fully informed consent of the individual concerned. Ironically, the characteristics of the target groups that make them scientifically very appealing also make it extremely difficult to deal with the cultural implications of the Project for each of the groups.

17. Financial or medical benefits can be a strong incentive for participation in the Project. The IBC report, however, noted the ethical problems of payment and stated that no undue compensation should be offered to ensure participation in sampling, which may be extremely difficult to control given the one-sided power relationship in the poorer areas of the world. The financial benefit should be seen in terms of communities, not individuals. It is suggested that other benefits can be passed on to the participants, for example, medical treatment and the anthropological and medical results of the research. There are possible difficulties that arise from these suggestions. Some see the provision of medical treatment in return for samples as merely a smokescreen that hides the lack of full consent. The returning to the participatory communities of the results derived may provide knowledge that is in conflict with a community's traditional beliefs relating, for example, to the origin of its people, which indigenous peoples may not want to know or to be known by others.

18. The HGDP is intended to be a widely accessible gene pool for general use, and would include important information regarding the origins of the samples. Indigenous groups have called for access to such information to be

limited in order to prevent the information from being used to the detriment of the group concerned. For example, if a group is found to have a genetically high risk of contracting a certain disease and an insurance company were to discover this, members of that community might be denied insurance coverage by that company. At the extreme, concerns have also been expressed that it is possible that this knowledge could be used in developing biological weapons targeted at the particular indigenous groups.

19. Research on human genome samples has led to advancements in the treatment of many diseases, including cancer and AIDS. Understandably, this knowledge is extremely valuable in financial terms and the patenting of human cell lines has become big business. The owner of a patent has legal rights over the subject of the patent and therefore to any profits that may be made therefrom. Opponents of patenting of human genes argue that the identification of a human genome is a discovery, not an invention, and is therefore not liable for patenting, as is the case for laws of nature which are deemed to be a discovery of something already in existence and therefore not invented.

20. Patenting of human genome material, however, does occur and has been accepted by courts in some countries. The ground-breaking case in the United States of America, Moore v. Regents of the University of California, determined that once human tissue had been taken with the consent of the person, he or she no longer had rights to that material and therefore could not gain financially from the research. In 1985, a United States businessman, Mr. John Moore, filed a lawsuit claiming that his blood cells were misappropriated while he was undergoing treatment for leukaemia at the University of California. During this treatment, Mr. Moore's doctor developed a cell line that was used in fighting cancer. The University filed a patent claim on the cell line and developed pharmaceuticals commercially using the cell line. The Supreme Court of California ruled that Mr. Moore did not have property rights to the cells taken from his body, and therefore had no claim to profits derived from research conducted on them.

21. Patents have also been filed on the cells of indigenous peoples. In 1993, the United States Secretary of Commerce filed a patent on the cell line of a 26-year-old indigenous Guaymi woman from Panama. The Guaymi people were found to have a particular virus and antibodies that are relevant to research on AIDS and cancer research. The patent claim was withdrawn after a public outcry, but since then United States authorities have had more success. For example, on 14 March 1995, an indigenous man of the Hagahai people of Papua New Guinea's remote highlands, had his DNA patented by the United States National Institute of Health. The patent covers a cell line containing unmodified Hagahai DNA. Between 1981 and 1995 a total of 1,175 patents for human DNA sequences were granted worldwide. More than three quarters of these patents are privately owned, most by companies based in Japan and the United States (Nature, vol. 380, 4 April 1996, pp. 387-388).

22. There are two primary arguments against the patenting of human materials. The first is that the patenting of any life - human, animal or plant - is objectionable in many cultures, for a variety of reasons including the respect for nature, religious beliefs, and the attitude that "some things are just not for sale". For many indigenous and other communities, the gift of blood is sacred and the involvement of profit-oriented corporations in this

transaction is seen as the commodification of humans and their bodies. The second is that in practice, the person who is the source of the material is unlikely to receive the financial benefits deriving from the patent, and any such benefit would rely on the generosity of the patent owner, not on any legal right. While the latter issue affects any participating individual and community, indigenous populations arguably have minimal access to the legal advice and political power necessary to secure an outcome satisfactory to them.

23. The organizers of the HGDP emphasize that the Project is not about making money but expanding knowledge, and that they do not intend to patent any samples or resultant products. They also state that any financial benefits should be returned to the sample populations. However, the aim of the Project is to develop a gene bank that is accessible to scientists generally. Even if the HGDP scientists are willing to recognize the rights of the sample populations, the scientists who later use the gene bank may not agree. Indeed, with the bulk of existing patents in private hands, commercial considerations are paramount in scientific research using human genome material.

24. Even if some form of compensation of participants is envisaged, it creates more difficult issues, particularly regarding the distribution of rights between the individual and the community. To whom should the benefits flow? In Western legal systems, legal rights are held by "legal persons" - an individual or registered company. The IBC report poses the question, "Can one individual sign away commercial rewards to future research knowledge for the population to which they belong?" If the answer is no, then how would funds be given to the community? A large amount of money injected into a relatively poor community may provoke irreparable damage to its traditional culture. The danger of commodification of humans may be enhanced, rather than slowed, by the payment of royalties. Conversely, to deprive the community of such funds is to ignore their essential contribution to the Project.

25. Compromises have been suggested, for example, creating a trust fund to be administered by an independent body for the benefit of the populations concerned. But this is no answer for those who consider that it is their right to maintain legal control of the products developed from or with the assistance of their genes.

Addressing the ethical and legal issues

26. Many interest groups, research bodies, legislatures and a number of international organizations have raised the issue of possible ethical and legal implications in the collection of human genome material. A number of indigenous organizations and representatives have called for the outright banning of human genome collection. For example, in February 1995 a forum of indigenous peoples of Asia issued a statement to the European Parliament in which they strongly opposed the HGDP and demanded that it be stopped. The Beijing Declaration of Indigenous Women formulated at the Fourth World Conference on Women in 1995 demanded that the Project be condemned and stopped, as have other communities, such as the group of indigenous organizations that met at the Ukupseni community in Kuna Yala, Panama in November 1997 and also adopted a declaration on the Project. In the Declaration of Indigenous Peoples of the Western Hemisphere Regarding the

Human Genome Diversity Project, 17 indigenous peoples' organizations in the Americas demanded that the HGDP and any related programmes be stopped, and that the United Nations and other international organizations work with indigenous peoples to protect all life forms from genetic manipulation and destruction.

27. The Rural Advancement Foundation International (RAFI), a non-governmental organization that has been instrumental in the protests against the HGDP and active in the Hagahai patent case mentioned above, is seeking stronger restrictions on the patenting of human genetic material in the intellectual property provisions of the General Agreement on Tariffs and Trade. RAFI has called for the recognition of two systems of values, the indigenous system, being the "cooperative innovation system", and that of modern science, the "institutional innovation system", and for the recognition of the contribution and value of the former to the world's food supplies, farming systems and medicinal needs.

28. There are a number of international human rights instruments that may have some bearing on this issue. The Universal Declaration of Human Rights, in article 3 states, "Everyone has the right to life, liberty and security of person", and in article 5, "No one shall be subject to torture or to cruel, inhuman or degrading treatment or punishment". Article 12 states, "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks on his honour and reputation. Everyone has the right to the protection of the law against such interference and attacks." The International Covenant on Civil and Political Rights, in article 17, echoes this right, though referring to "unlawful" attacks. Article 15 (1) of the International Covenant on Economic, Social and Cultural Rights states that everyone has the right:

"(a) To take part in cultural life;

"(b) To enjoy the benefits of scientific progress and its applications;

"(c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author."

The Proclamation of Tehran, in paragraph 18, states, "While recent scientific discoveries and technological advances have opened vast prospects for economic, social and cultural progress, such developments may nevertheless endanger the rights and freedoms of individuals and will require continuing attention." The UNESCO Declaration on Race and Racial Prejudice, article 1, states:

"1. All human beings belong to a single species and are descended from a common stock. They are born in equal dignity and rights and all form an integral part of humanity.

"2. All individuals and groups have the right to be different, to consider themselves as different and to be regarded as such. However, the diversity of life styles and the right to be different may not, in any circumstances, serve as a pretext for racial prejudice; they may not

justify either in law or in fact any discriminatory practice whatsoever, nor provide a ground for the policy of apartheid, which is the extreme form of racism.

"3. Identity of origin in no way affects the facts that human beings can and may live differently, nor does it preclude the existence of differences based on cultural, environmental and historical diversity nor the right to maintain cultural identity.

"4. All peoples of the world possess equal facilities for attaining the highest level in intellectual, technical, social, economic, cultural and political development.

"5. The differences between the achievements of the different peoples are entirely attributable to geographical, historical, political, economic, social and cultural factors. Such differences can in no case serve as a pretext for any rank-ordered classification of nations or peoples."

29. The IBC report referred to above was followed by the *Universal Declaration on the Human Genome and Human Rights*, adopted unanimously at the twenty-ninth session of the UNESCO General Conference on 11 November 1997. The Declaration addresses many of the concerns of indigenous people, while also acknowledging the benefit to humankind of valuable discoveries that can come from study of the human gene. Therefore, it does not call for the abolition of the collection of human genome samples, but rather seeks to set international standards ensuring the human rights of participants. The United Nations Commission on Human Rights at its forty-third session adopted resolution 1997/71 entitled "Human rights and bioethics" in which it referred to the need to preserve the dignity and integrity of the human being and to ensure that scientific progress benefited individuals and developed in a manner respectful of fundamental human rights.

30. Other organizations have also been involved in the setting of standards for this work. The Human Genome Organization (HUGO), the international coordinating body for human genetics studies endorsed in March 1996 a Statement on the Principal Conduct of Genetic Research drawn up by its Ethical, Legal and Social Issues Committee. The Committee based its recommendations on four principles: recognition that the human genome is part of the common heritage of humanity; adherence to the international norms of human rights; respect for the values, traditions, culture and integrity of participants; and acceptance and upholding of human dignity and freedom. The Committee recommended that "undue inducement" through compensation for individuals, families and population groups taking part in gene mapping should be prohibited, but that agreements might be made, inter alia, for the provision of health care or information structures or for the possible use of a percentage of any royalties for humanitarian purposes.

31. The recommendations also referred to the need to obtain informed consent "free from coercion by scientific, medical, or other authorities". Such consent could be "individual, familial, or at the level of communities and populations". This question is seen as problematic in some quarters as it implies that scientists may not need to gain individual consent.

32. HUGO's Intellectual Property Rights Committee prepared a Statement on Patenting Issues Related to Early Release of Raw Sequence Data in late 1997, approved by the Council of HUGO, in which the organization reaffirmed its opposition to the patenting of "short sequences from randomly isolated portions of genes encoding proteins of uncertain functions", but clarifying that it did not oppose the patenting of "useful benefits derived from genetic information".

33. The 93rd Inter-Parliamentary Conference adopted by consensus a resolution on bioethics in which it stressed the urgent need, inter alia, to develop international principles which respect cultural diversity, prohibit financial gain from human products and ban the patenting of human genes. The Organization of African Unity, at its 32nd Ordinary Session, pledged to promote respect for the rights of individuals in relation to this issue and to encourage member States to legislate on and create consultative bodies to monitor this question. The European Convention on Human Rights and Biomedicine, in article 21, states "The human body and its parts shall not, as such, give rise to financial gain" (this does not include hair and nails, sources of DNA, as their collection is deemed not to be an affront to human dignity). The IBC report notes that this may be considered a Western judgement.

34. Individual countries have also taken steps to address these issues. India has been developing legislation to ensure that those providing DNA samples are entitled to a share of royalties from their use. There is a possibility that some Pacific nations may ask the International Court of Justice for an Advisory Opinion on the morality of patents on human genes and are developing a "Lifeforms Patent-Free Pacific Treaty". Some other countries have legislation dealing with ethics in medicine.

35. Not all States are supportive of the banning of patenting of human products. During the 1992 Earth Summit in Rio de Janeiro, the United States, one of the largest partners in the HGDP Project, expressed the view that genes of plants and animals belong to a common international heritage, and accordingly are not owned by their keepers. The implications of this view are that any financial benefits gained from these items will go to those who manipulate the genetic repository to commercial advantage. Many people from developing counties, where most of the genetic diversity is found, reject this as an exclusively first world view. Recent advice issued by the Patent and Trademark Office of the United States Department of Commerce, however, indicates a possible change in attitude. The Office warns that, "inventions directed to human/non-human chimera could, under certain circumstances, not be patentable because, among other things, they would fail to meet the public policy and morality aspects of the utility requirement" of patent law, as courts have interpreted the utility requirement to exclude inventions deemed to be "injurious to the well-being, good policy, or good morals of society". (Lowell v. Lewis, Fed. Cas. No. 8568 (C.C. Mass. 1817), quoted in Tool-O-Matic Inc. v. Proma Product - und Marketing Gesellschaft M.b.H., 945 F.2d 1546, 1552, 20 USPQ2d 1332, 1338 (Fed. Cir. 1991)).

The future of the HGDP

36. Unlike statements of many indigenous representatives, neither the IBC report nor the UNESCO Declaration call for Projects such as the HGDP

to be abandoned. Rather, they emphasize the need to consider basic human rights in population genetics, and address a number of the concerns with suggestions on how problems can be, at least to some extent, overcome. For example, they call for indigenous groups and community representatives to be included in discussions of the Project and urge researchers to consider the history of the group that they plan to include in their research, taking into account matters not only of scientific interest, but also the ethical, social and ideological impact on the group of the research.

37. The IBC report emphasizes the need for "informed consent" by defining certain minimum information, in the subject's own language, before asking someone to consent to any sampling or treatment, including a basic description of the procedure and a description of the risks and benefits of the resultant information. The report notes, however, that the likelihood of obtaining truly informed consent is virtually impossible, particularly as it can never be ascertained for certain that information provided to people is completely understood. The report therefore concludes that the question is not so much one of "informed consent" as of ensuring that scientists properly inform potential participants, taking into consideration the cultural and religious needs and aspirations of the community.

38. The report also addresses the issue of collective consent to be the subject of study. Government approval needs to be secured in the first instance, and this needs to be complemented by consent from the individuals and the local groups/communities selected for the study, whether the consent is obtained directly or through formal/informal leadership, group representative or trusted intermediaries. Consent would need to be obtained from the most appropriate persons, taking into account the group's social structure, values, laws, goals and aspirations, and it must be ensured that the actual physical removal of samples of saliva, skin, hair, or blood do not violate cultural norms. The form in which consent is given will need to be discussed and agreed upon by each community.

Conclusion

39. The Human Genome Diversity Project continues, despite the objections of many indigenous peoples. It is arguable that there is a developing awareness of and sensitivity to the ethical and legal issues surrounding the collection of human genome. Many projects in this area now have an ethical, legal and social implications (ELSI) component, ensuring that a certain percentage of the Project budget is devoted to issues such as informed consent, privacy and education. It is possible that some of the concerns of indigenous peoples can be addressed through international and local desire to improve consultation with indigenous peoples and through changes in patent law. Some concerns of indigenous peoples, however, cannot be adequately addressed without a complete ban on projects such as the HGDP, and of the patenting of human genome materials.